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## **HRB Statistics Series 33**

# Annual Report of the National Intellectual Disability Database Committee 2016 Main Findings

Anne Doyle, Sarah Hourigan and Sarah Fanagan

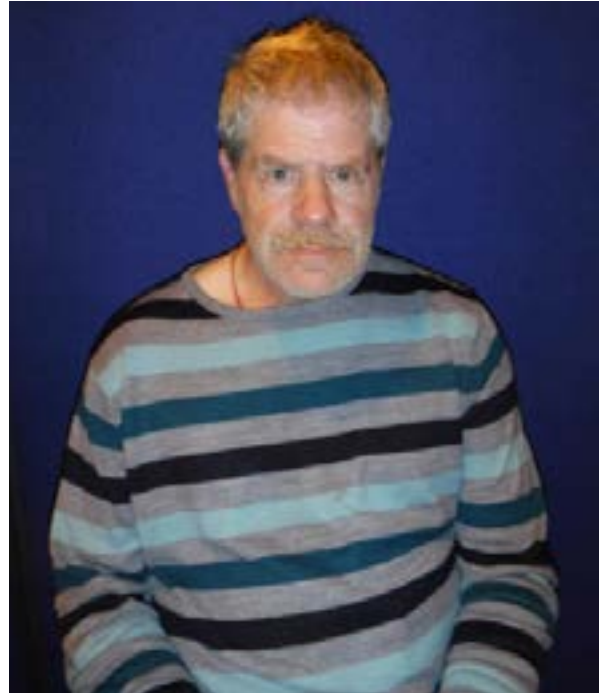
Research. Evidence. Action.

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**'Emerald Forest' by John Murphy**  
**NIDD Cover Design Winner 2016**

My name is John; I live in Artane with five other housemates. My place is an apartment which is attached to the main house. I go to 'Castle Industries' in Coolock Monday to Friday where I participate in activities such as golfing, which I go to once a week. I also attend the local gym twice weekly and attend art classes in my local community in Artane. I also attend computer courses as I have a keen interest in reading, writing and history.

In Castle Industries we have an allotment that I attend on a regular basis as we grow fruit and veg which I enjoy. I visit my parents who are both elderly and have coffee and chat and help Dad out in the garden. I also enjoy hiking around Howth Harbour and getting fish and chips afterwards.



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# About the HRB

The Health Research Board (HRB) is the lead agency supporting and funding health research in Ireland. We also have a core role in maintaining health information systems and conducting research linked to these systems. Our aim is to improve people's health, build health research capacity, underpin developments in service delivery and make a significant contribution to Ireland's knowledge economy.

## Our information systems

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The HRB is responsible for managing five national information systems. These systems ensure that valid and reliable data are available for analysis, dissemination and service planning. Data from these systems are used to inform policy and practice in the areas of alcohol and drug use, disability and mental health.

The **HRB Statistics Series** compiles data on problem alcohol and drug use, disability and mental health from a single point or period in time. Previous reports associated with this series are:

- » *Activities of Irish Psychiatric Units and Hospitals*
- » *National Physical and Sensory Disability Database Committee Annual Reports*
- » *National Intellectual Disability Database Committee Annual Reports.*

The **Disability Databases Team** manages two national service-planning databases for people with disabilities on behalf of the Department of Health: the National Intellectual Disability Database (NIDD), established in 1995, and the National Physical and Sensory Disability Database (NPSDD), established in 2002. These databases inform decision-making in relation to the planning of specialised health and personal social services for people with intellectual, physical or sensory disabilities.

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# Acknowledgements

The National Intellectual Disability Database Committee wishes to acknowledge the continuing commitment and co-operation of the following groups who are involved in the ongoing maintenance of the National Intellectual Disability Database:

- » Disability Unit, Department of Health;
- » the Health Service Executive, in particular the database coordinators and the database administrators/managers;
- » service providers;
- » the National Federation of Voluntary Bodies providing services to people with intellectual disability;
- » the parents and families of people with an intellectual disability and their representative bodies; and all service users throughout Ireland.

The Committee would also like to acknowledge the outgoing Chairperson, Gráinne Duffy, for her enthusiasm and support for the databases over the past four years and to welcome Ms Patsy Carr as its new Chairperson.



# Members of the National Intellectual Disability Database Committee 2016

<p><b>Ms Gráinne Duffy (Chairperson)</b> Disability Unit Department of Health</p>	<p><b>Mr Billy McCarthy</b> Disability Unit Department of Health</p>
<p><b>Ms Margaret Dorney (Secretary)</b> Disability Unit Department of Health</p>	<p><b>Mr James Roche</b> Western Care Association Representing the National Federation of Voluntary Bodies</p>
<p><b>Mr Harry Harris</b> Disability Unit Department of Health</p>	<p><b>Mr Declan Ryan</b> St Michael's House Representing the National Federation of Voluntary Bodies</p>
<p><b>Dr Máirín Boland</b> Department of Public Health Health Service Executive</p>	<p><b>Dr Sarah Craig</b> Health Research Board</p>
<p><b>Ms Joan O'Connor</b> Disability Federation of Ireland</p>	<p><b>Ms Mary O'Gorman</b> Health Research Board</p>
<p><b>Mr Gerard Tully</b> National Disability Unit Health Service Executive</p>	<p><b>Ms Anne Doyle</b> Health Research Board</p>
<p><b>Mr Dharragh Hunt</b> National Disability Authority</p>	<p><b>Ms Anne O'Donohoe</b> Health Research Board</p>
<p><b>Ms Fionnuala O'Donovan</b> Chief Executive Enable Ireland</p>	<p><b>Ms Anne Marie Carew</b> Health Research Board</p>
<p><b>Ms Claire Collins</b> Disability Unit Department of Health</p>	<p><b>Ms Caraiosa Kelly</b> Health Research Board</p>

## 1

# Introduction

This report presents the main findings of the analysis of data from the National Intellectual Disability Database (NIDD). The report is based on validated data extracted from the NIDD in December 2016. The 2016 dataset consists of information relating to 28,275 people. Of these registrations, 84.8% (23,978 records) were updated following the 2016 annual review of NIDD information; the remaining 4,297 registrations contain the last-known data in each case.<sup>1</sup> Prevalence rates per thousand of population are based on data from the 2011 Census of Population.<sup>2</sup> Comparative data for 1996 and 2015 used in this report are from published NIDD data for these years.

In addition to this report, a complete set of tables and figures, mirroring data in reports from 2015 and previous years, is available in MS Excel versions on the HRB website at [www.hrb.ie](http://www.hrb.ie).

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1. The majority of the cases not reviewed were due to resource issues in two HSE areas

2. Central Statistics Office (2012) Census of Population, 2011: Principal demographic results. Dublin: Stationery Office.

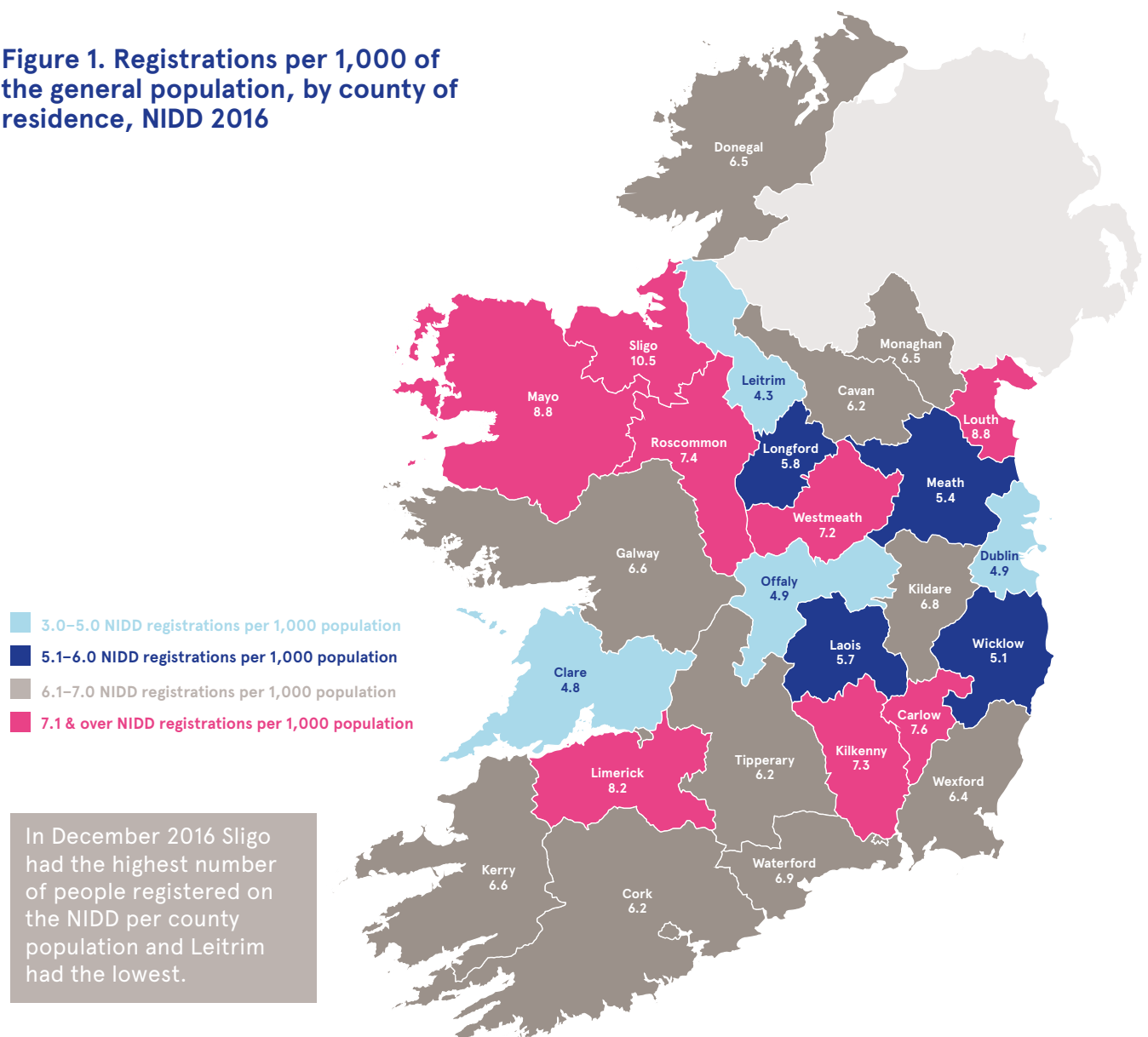
# 2

## Profile of the registered population

There were 28,275 people registered on the NIDD at the end of December 2016. Based on 2011 Census of Population figures, this represents a prevalence rate of 6.16 per 1,000 population. The prevalence rate for mild intellectual disability (which traditionally has been under-reported) was

2 per 1,000, and the rate for moderate, severe or profound intellectual disability was 3.59 per 1,000. Figure 1 presents the number of registrations by county of residence and shows that Sligo (10.5/1,000) had the highest prevalence rate while Leitrim (4.3/1,000) had the lowest.

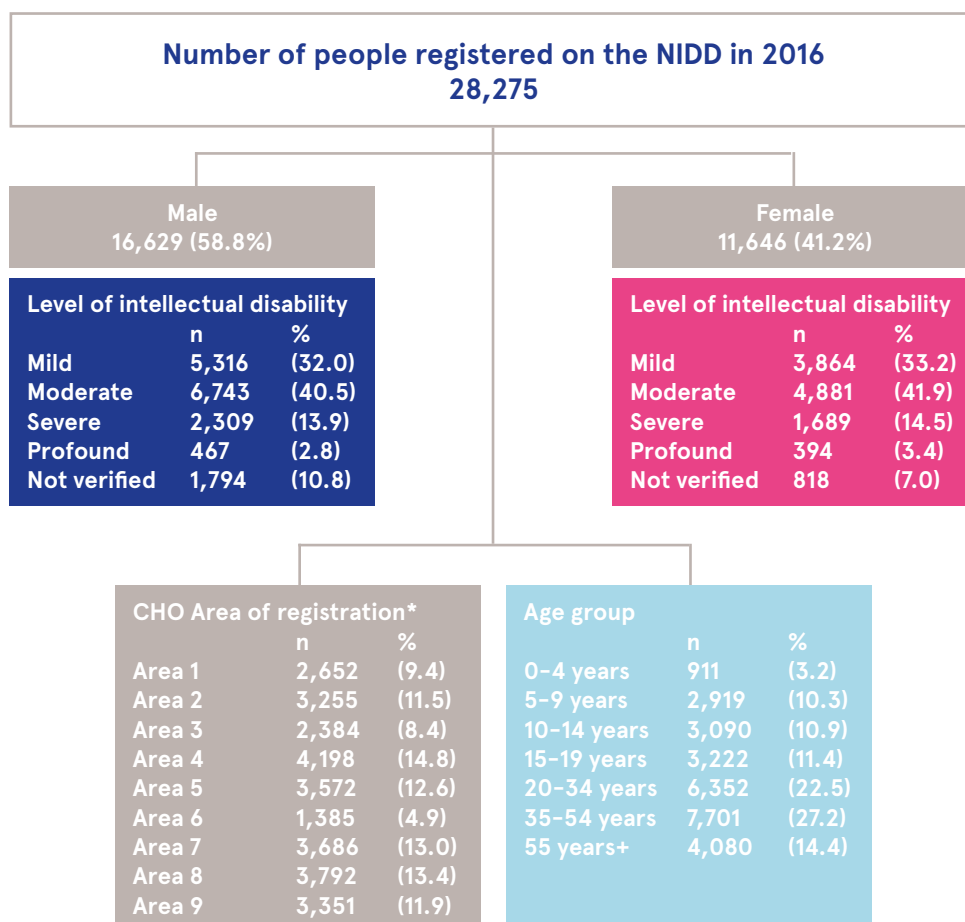
**Figure 1. Registrations per 1,000 of the general population, by county of residence, NIDD 2016**



In December 2016 Sligo had the highest number of people registered on the NIDD per county population and Leitrim had the lowest.

Figure 2 below displays a summary profile of the number of people registered on the NIDD in 2016 by gender, age group and CHO area of registration.

**Figure 2. Profile of the population registered, NIDD 2016**



**\* The 9 Community Health Organisations (CHOs) are:**

**Area 1** - Donegal, Sligo/Leitrim/West Cavan, Cavan/Monaghan

**Area 2** - Galway, Roscommon, Mayo

**Area 3** - Clare, Limerick, North Tipperary/East Limerick

**Area 4** - Kerry, North Cork, North Lee, South Lee, West Cork

**Area 5** - South Tipperary, Carlow/Kilkenny, Waterford, Wexford

**Area 6** - Wicklow, Dun Laoghaire, Dublin South East

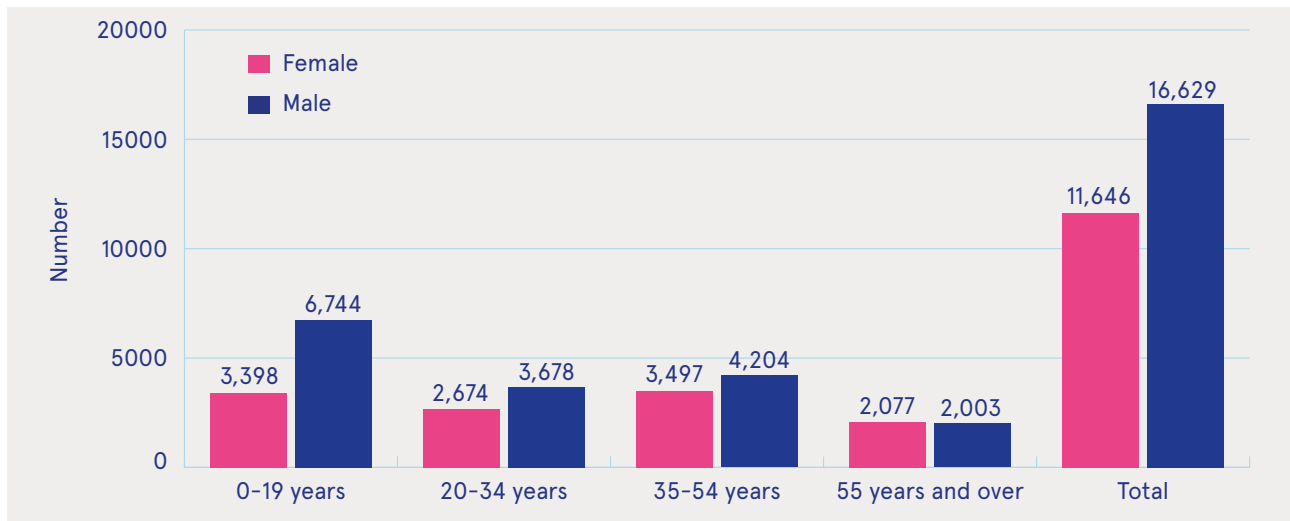
**Area 7** - Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West

**Area 8** - Laois/Offaly, Longford/West Meath, Louth/Meath

**Area 9** - Dublin North, Dublin North Central, Dublin North West

There were more males than females registered with an intellectual disability in all age groups except those aged 55 years and over, with an overall ratio of 1.43 to 1 (Figure 3).

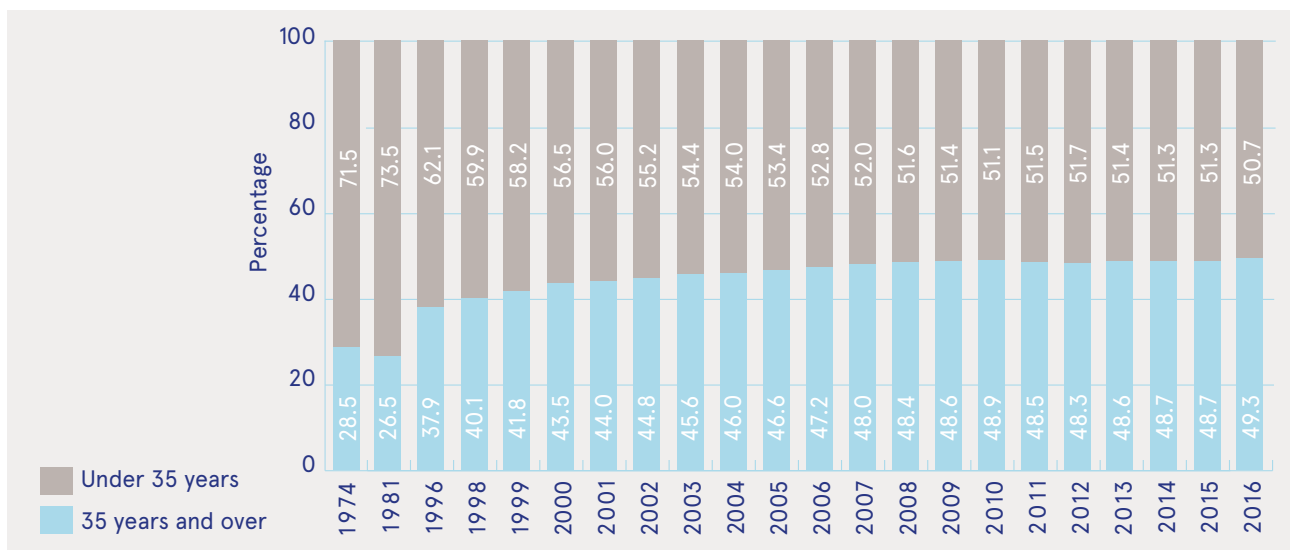
**Figure 3. Number of people registered by age group and gender, NIDD 2016**



The total number of people recorded as having moderate, severe or profound intellectual disability has increased by 46.4% since the first Irish Census of Mental Handicap<sup>3, 4</sup> – as it was referred to then – was carried out more than forty years ago in 1974. Some of the factors contributing to this increase in numbers is the growth in the general population over the period, resulting from increased births, a reduction in the number of deaths and an increase in net migration. Of the people with moderate, severe or profound intellectual disability, the percentage aged 35 years and over increased from

28.5% in 1974 to 37.9% in 1996 when NIDD data were first reported, and to 49.3% in 2016 (Figure 4). These figures reflect an increase in the lifespan of people with intellectual disability and over the past ten years the proportion aged 35 years and over has ranged from 48.0% to 49.3%. This changing age profile, observed in the data over the past four decades, has implications for service planning; as there is a continuing high level of demand for services designed to meet the needs of older people with intellectual disability, in addition to support services for ageing care givers.

**Figure 4. Percentage of people with moderate, severe or profound intellectual disability (combined) by age group 1974–2016, NIDD 2016**



3. Mulcahy M (1976) Census of the mentally handicapped in the Republic of Ireland 1974: non-residential. Dublin: Medico-Social Research Board.

4. Mulcahy M and Ennis B (1976) Census of the mentally handicapped in the Republic of Ireland 1974: residential. Dublin: Medico-Social Research Board

## 3

# Service provision in 2016

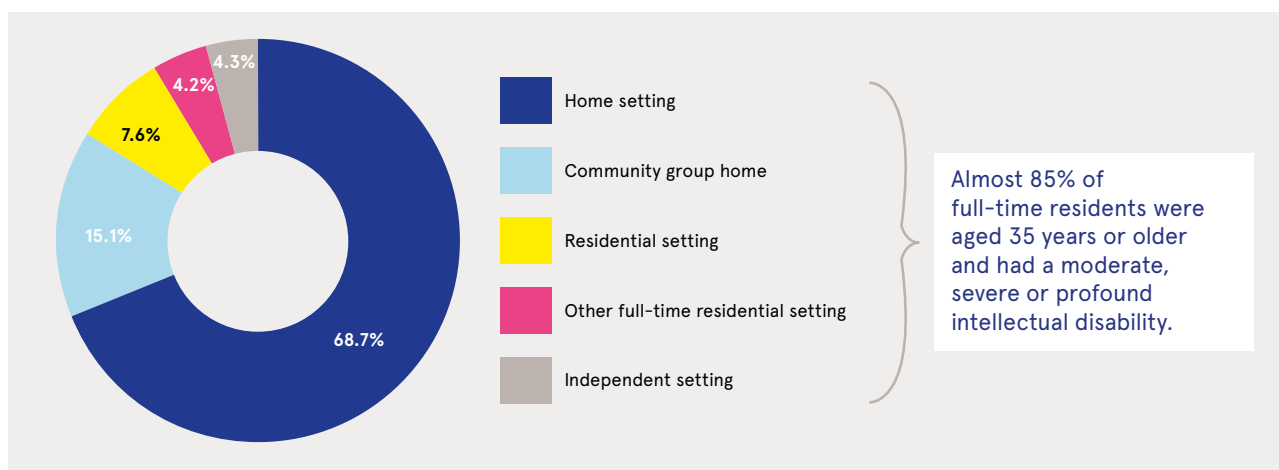
The numbers registered on the NIDD in December 2016 were as follows:

- » 27,863 people with intellectual disability were in receipt of services, representing 98.5% of the total population registered on the NIDD.
- » 239 people (0.8% of those registered) were not availing of services in 2016 and were identified as requiring services in the period 2017–2021.
- » 173 people (0.6%) were not availing of services and had no identified requirement for services during the planning period 2017–2021.
- » 19,416 people (68.7%) lived at home with parents, siblings, relatives or foster parents in 2016. Almost one third of people (2,513, 30.9%) aged 35 years or over with moderate, severe or profound intellectual disability lived at home in 2016. As people with intellectual disability live longer, their service use and need and that of their carers changes which has implications for service-planning.

Of the 27,863 people who were in receipt of services in 2016:

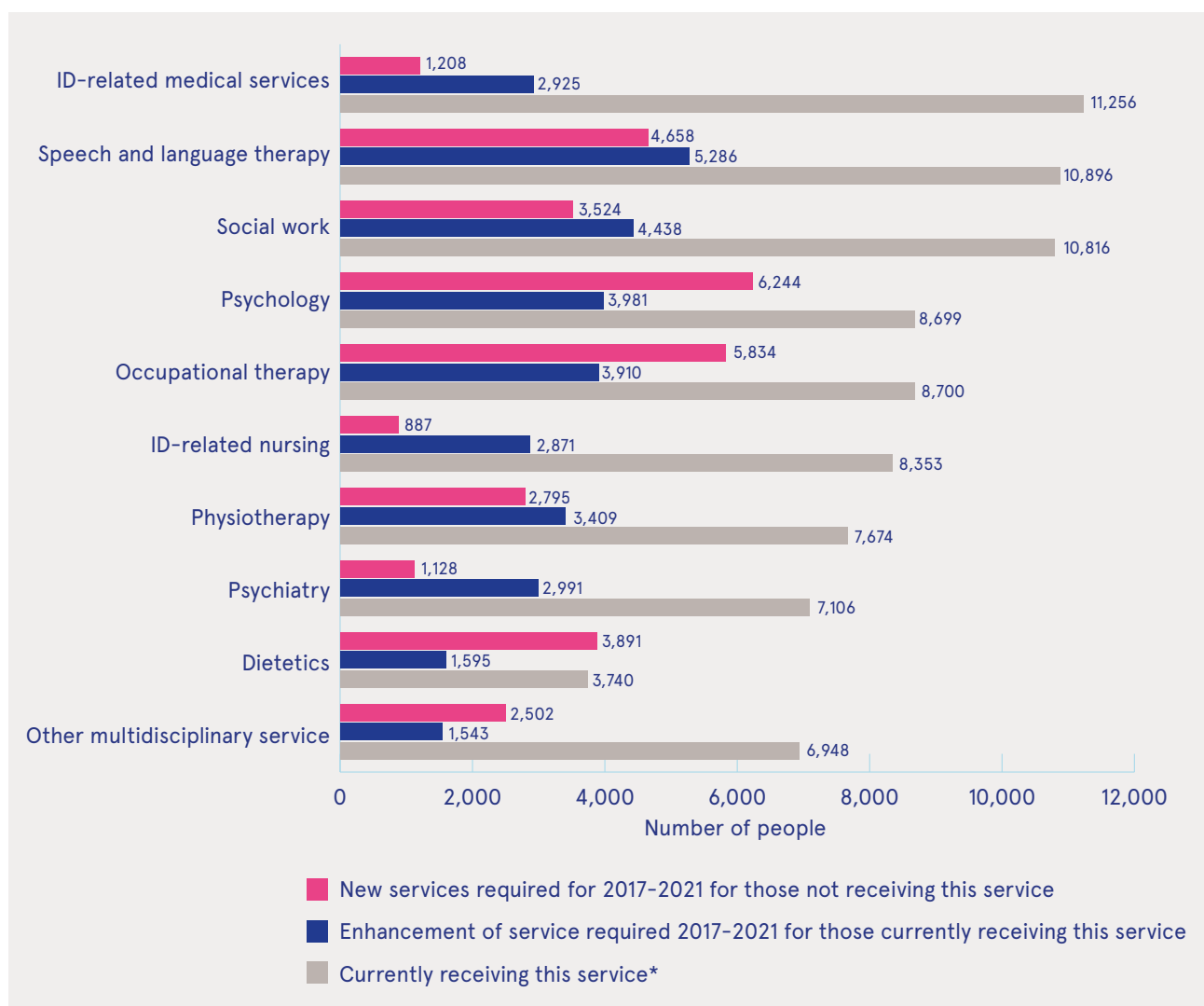
- » 7,612 (27.3%) were in receipt of full-time residential services, a decrease of 1.5% from the 2015 figure. The data indicate that more people live in community group homes than in residential centres (Figure 5).
- » Of the 7,612 full-time residents, 6,288 (82.6%) had a moderate, severe or profound level of intellectual disability, 6,541 (85.9%) were aged 35 years or over, 4,279 (56.2%) were living in community group homes and 2,135 (28.0%) were living in residential centres.
- » 27,813 (99.8%) people availed of at least one day programme in 2016. This is the highest number registered as receiving such services since NIDD data were first reported in 1996. Not all of these services are HSE funded. Of this group, 7,582 people (27.3%) were in full-time residential care.

**Figure 5. Main residential circumstance, NIDD 2016**



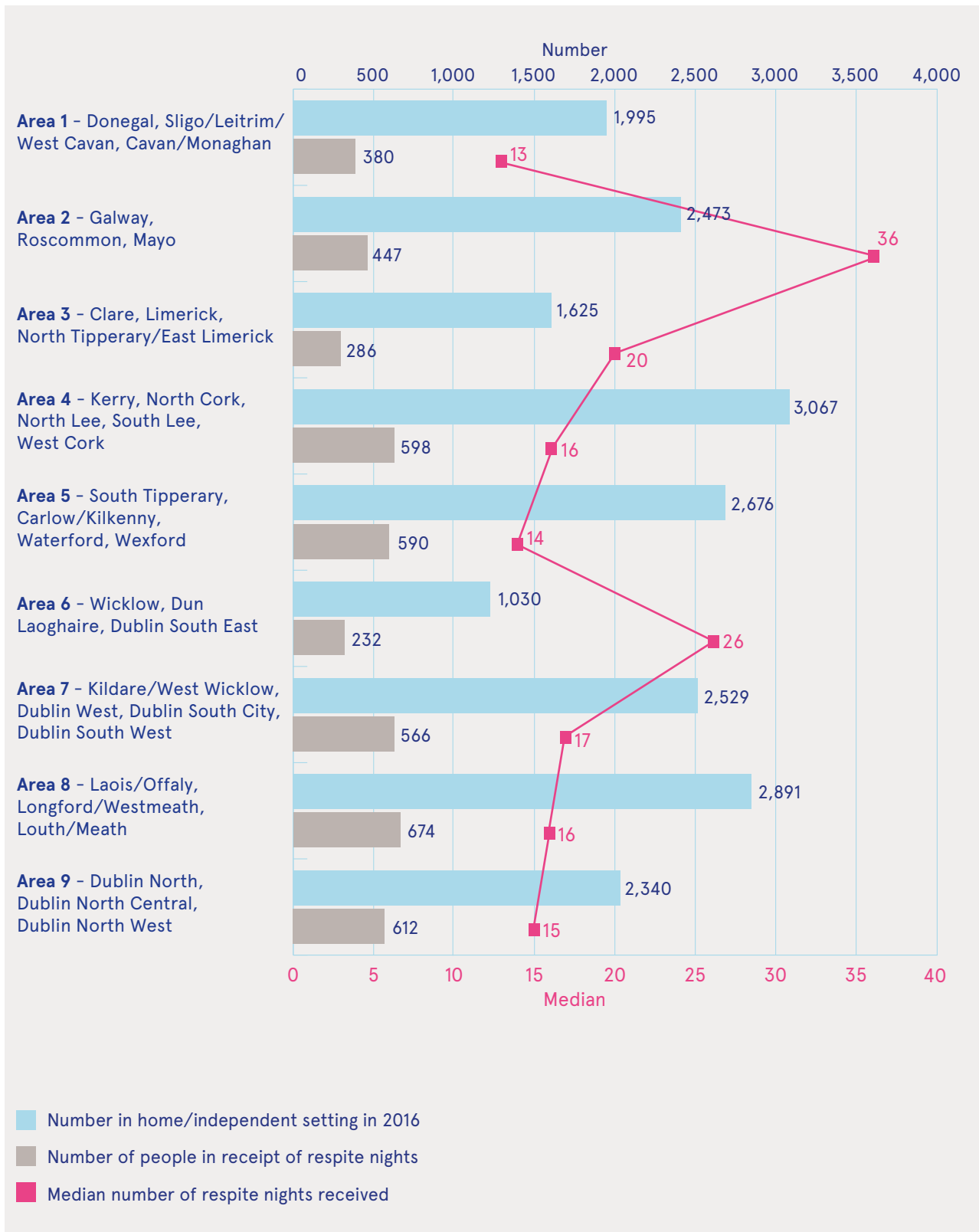
- » 23,811 people (85.5%) availed of one or more multidisciplinary support service (Figure 6) – this varies by CHO area. The services most commonly availed of by adults were social work, medical services and psychiatry. The services most commonly availed of by children were speech and language therapy, occupational therapy and physiotherapy.
- » The number of people with intellectual disability accommodated in psychiatric hospitals decreased by 6 (3.9%), from 154 in 2015 to 148 in 2016. More than two thirds (105, 70.9%) were residing in CHO area 9; and over one third (56, 37.8%) require a transfer to an alternative residential facility in the period 2017–2021.
- » In 2016, a total of 4,385 people received respite around the country with a median of 17 nights received. The data showed marked differences between CHO areas with the number of people ranging from 286 in CHO 3 (Clare, Limerick, North Tipperary/East Limerick) to 674 in CHO 8 (Laois/Offaly, Longford/Westmeath, Louth/Meath) and the median number of nights received ranging from 13 in CHO 1 (Donegal, Sligo/Leitrim/West Cavan, Cavan/Monaghan) to 36 in CHO 2 (Galway, Roscommon, Mayo) (Figure 7).

**Figure 6. Multidisciplinary support services received in 2016 and required in the period 2017–2021, NIDD 2016**



\*Further analysis on current services is available by CHO area in the full set of NIDD tables and figures 2016 on the HRB website.

**Figure 7. Use of respite nights by CHO area of residence, NIDD 2016**





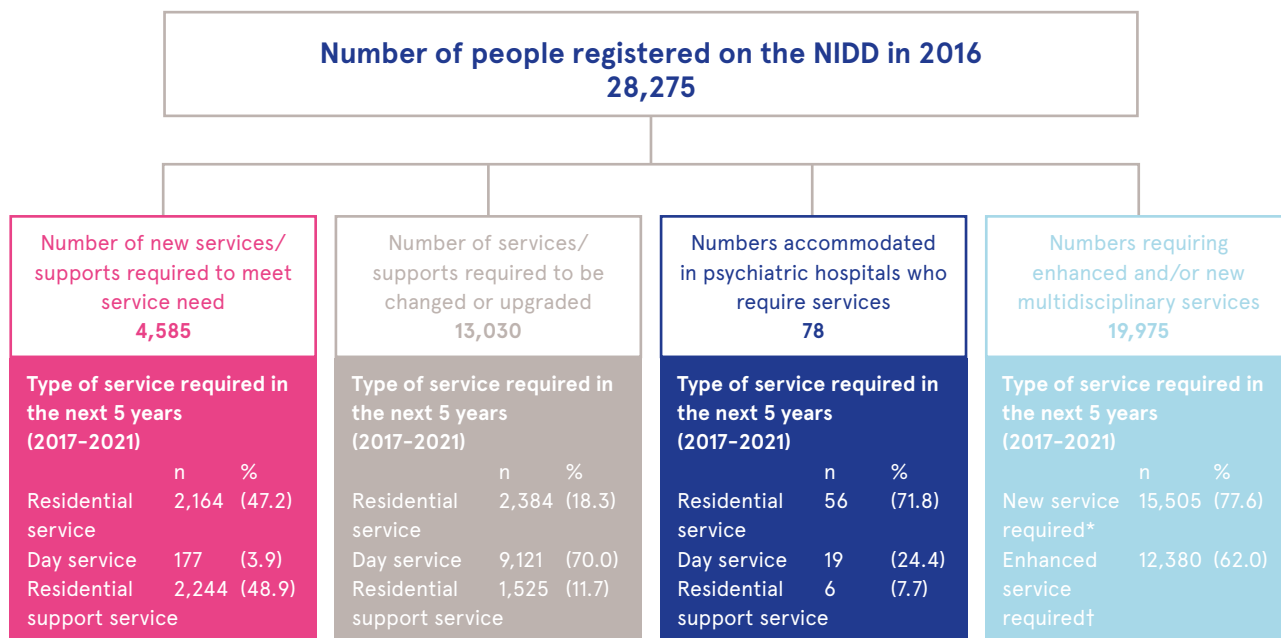
# 4

## Future service requirements 2017-2021

The NIDD collects information on the service requirements that people with intellectual disability, their families and key workers identify as a required need for the next five years. Figure 8 provides summary data on the four distinct categories of requirements for the five-year period, 2017-2021:

- » New services required
- » Required changes to existing services
- » Services required by those accommodated in psychiatric hospitals
- » New or enhanced multidisciplinary services.

**Figure 8. Summary of service requirements, NIDD 2016**



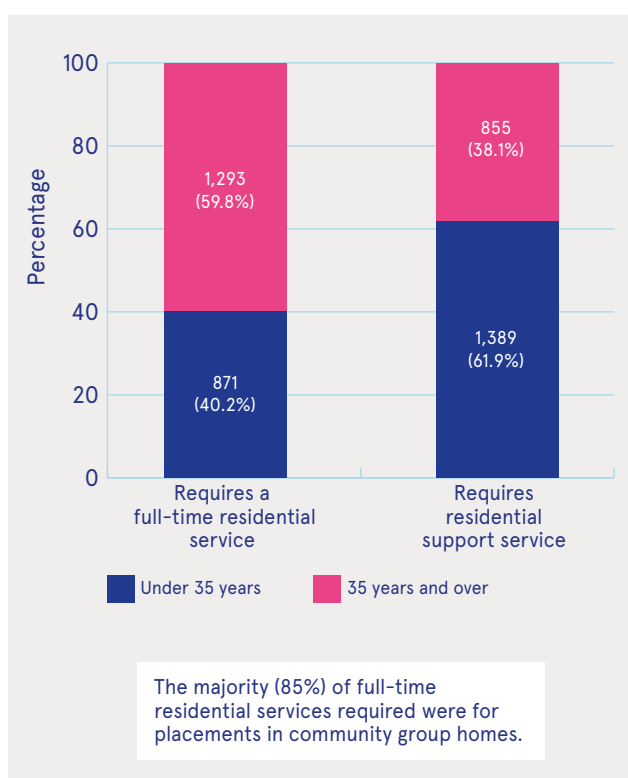
\* 'New service required' refers to a new type of therapeutic service that the individual does not currently receive.  
 † 'Enhanced service required' refers to a change in the delivery of a therapeutic service that the individual currently receives. There are 7,910 people whose multidisciplinary support service change involves both a new service and an enhanced service, therefore the actual number of people requiring a new and/or enhanced service is (15,505 + 12,380) - 7,910 = 19,975

## Unmet need

The 2016 data indicate that 4,585 new residential, day and residential support services will be needed to meet the requirements of those who do not currently avail of these services. The following services will be needed in the period 2017–2021 (most service needs were recorded as being immediate):

- » 2,164 new full-time residential placements (Figure 9), a decrease of three places, or 0.1%, on the projected number required in 2015. Almost three quarters (1,537, 71.6%) of this group had a moderate, severe or profound level of intellectual disability and 59.8% (1,293 people) were aged 35 years and over. The majority (1,846, 85.3%) require placements in community group homes.
- » 2,244 new residential support services, an increase of 111 on the projected number required in 2015. The majority of this group (2,023, 90.2%) live at home or independently in the community (Figure 9).

**Figure 9. Unmet need – number of people requiring residential service or residential support service by age group 2017–2021, NIDD 2016**



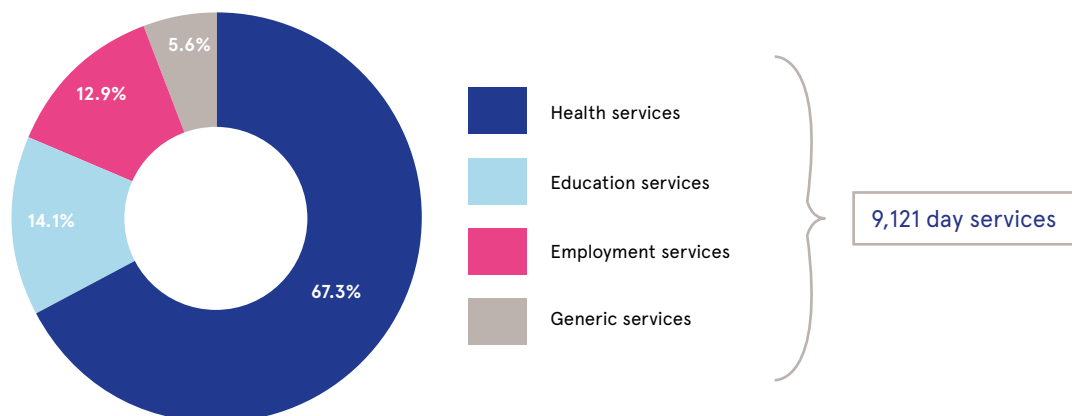
- » 177 day programmes (this figure excludes multidisciplinary support services (Figure 6) and services provided by early intervention teams). This number is in addition to the services required by 752 young adults who, as they approach the age of 18, are preparing to leave the education system to take up a range of training and supported employment opportunities.
- » Fifty-six people who were living in psychiatric hospitals in 2016 have been identified as needing to transfer from these locations to more appropriate accommodation such as community group homes or intensive placements for profound/multiple disabilities and/or challenging behaviour. The majority of those requiring a transfer were registered in the CHO area 9.

## Service change

Of those in receipt of services in 2016, 10,679 (38.3%) people require alternative, additional, or enhanced services in the period 2017–2021 (resulting in a total number of 13,030 changes required), a decrease of 380 (3.5%), since 2015. This group includes people who require an increased level of service provision, additional support within their existing services, transfer to more appropriate placements, or a service change to coincide with a transition period in their lives, such as a move from child to adult services, or from education to training and/or employment placements. To address the required service changes over the next five years:

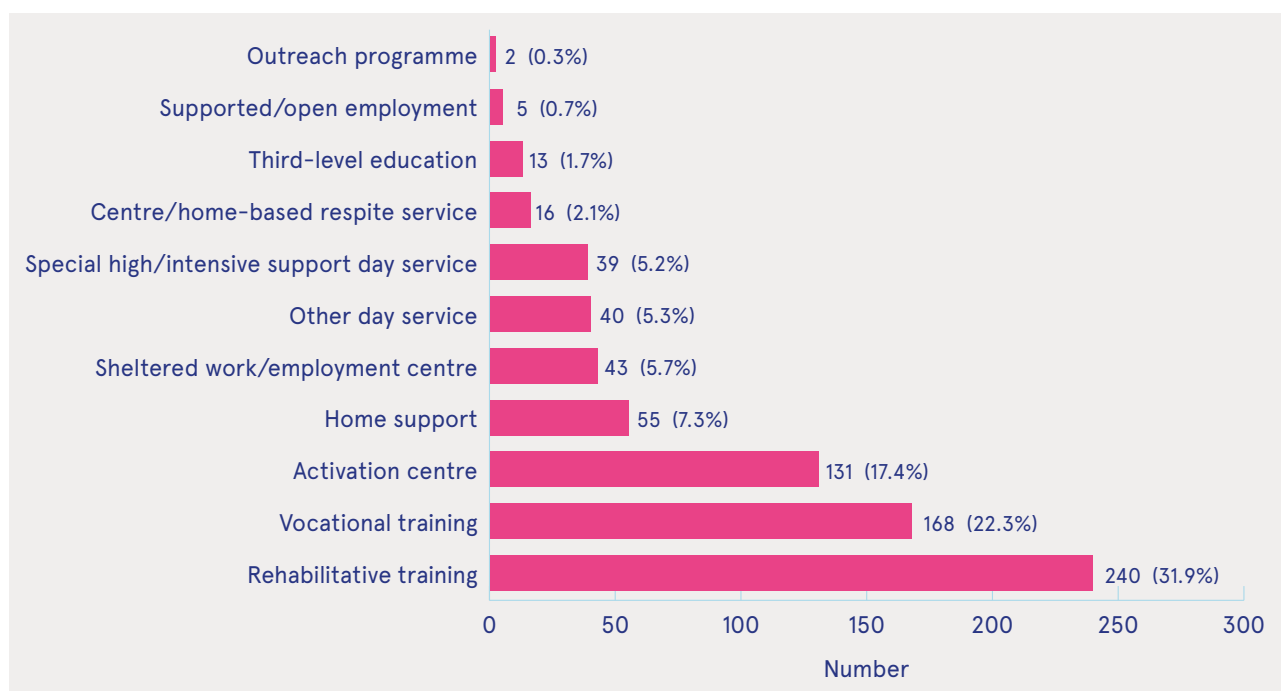
- » 9,121 day places will require changes or enhancements (Figure 10). The majority are for health-funded services which are required by 6,140 people (67.3%). Education services are required by 1,290 people (14.1%), employment services are required by 1,176 people (12.9%), and services such as training in domestic tasks or work skills required by 515 people (5.6%).

**Figure 10. Number and type of day services requiring change or enhancement 2017–2021, NIDD 2016**



» Of the 752 young people (aged 16–19 years) who were in an education setting in 2016, 240 (31.9%) require rehabilitative training, 168 (22.3%) require vocational training and 131 (17.4%) require activation programmes in the next five years 2017–2021 (Figure 11).

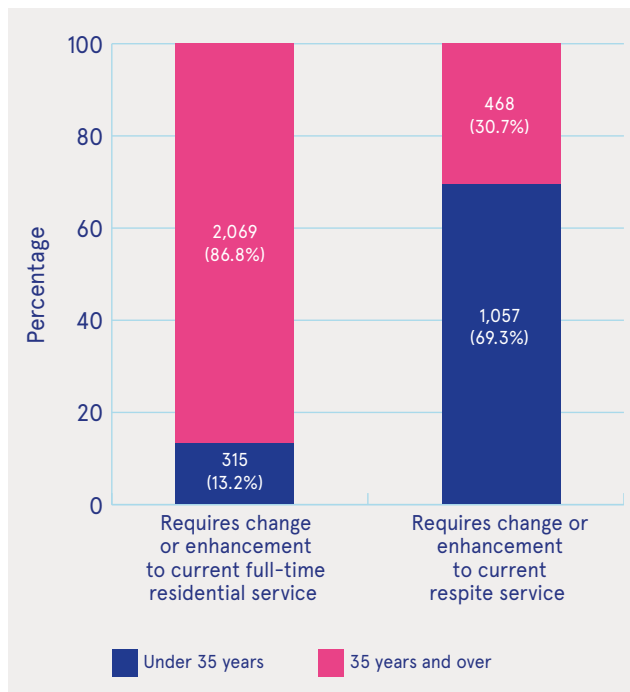
**Figure 11. Future day service requirements of people aged 16–19 years in an education setting 2017–2021, NIDD 2016**



» 2,384 people in full-time residential places require changes or enhancements to their service. 1,625 (68.2%) of this group require a move to a community group home and 516 (21.6%) to an intensive placement, for either challenging behaviour or multiple disabilities. The majority of this group (2,153, 90.3%) had moderate, severe or profound intellectual disability and 2,069 (86.8%) were aged 35 years or older (Figure 12).

» 1,525 people require changes or enhancements to their residential support places. Most of this need was for more frequent centre-based crisis or planned respite breaks for people already availing of this service (1,032, 67.7%).

**Figure 12. Service change – number of people requiring a change to, or enhancement of, their current service by age group 2017–2021, NIDD 2016**



Despite high levels of service provision in 2016, there remains a significant demand for new and enhanced multidisciplinary support services.

Seventy-one percent of those registered on the NIDD (19,975 people) require a new and/or enhanced multidisciplinary support service in the period 2017–2021. The main therapeutic services required are psychology, occupational and speech and language therapies (Figure 6).



## 5

# Summary

This report and associated tables are based on information collected from 28,275 people registered on the database at the end of December 2016, and it represents the recorded service use and needs of this group of people. Notable points from this report include:

- » The majority of adults with intellectual disability continue to live with their families with the aid of additional support services. As their caregivers age, a wide range of additional services are required for people who wish to continue to live as independently as possible.
- » The improved life expectancy among adults with severe intellectual disability has placed an ever-increasing demand on full-time residential services as fewer places are becoming free over time. Older service users availing of day and residential services also require a higher degree of support within these services, including additional medical services to meet their specific needs.
- » There is a continuing shift away from the more traditional institutional models of care towards community-based living arrangements for those requiring residential services. This is set to continue as funding is made available for decongregation.
- » The proportion of those registered who are in receipt of day services continues to rise. Many of those in receipt of day services are also benefiting from additional supports, such as home support, home help and respite services.
- » The demand for services for school leavers remains high, particularly in the areas of training and employment.
- » The level of provision of multidisciplinary support services in 2016 was high and future demand for these services continues for the five-year period 2017–2021. There was an increase in residential support provision between 2015 and 2016.
- » High levels of unmet need continue to exist among a significant number of people who are registered on the NIDD, particularly those who are aged 35 years and over and require a full time residential place in the next 5 years.

A full set of tables and figures based on 2016 NIDD data are available on the HRB website [www.hrb.ie](http://www.hrb.ie).





